

Appendix 4

Caring for Washington Individuals with Autism Task Force

Background – Emerging Themes

Autism is a developmental disorder that affects a person's ability to communicate and socially relate to others. Autism is not a rare disorder. It affects 1 per 166 people and is more common than Down Syndrome, childhood cancer, and deafness. At that rate, almost every citizen of our state is likely to know someone with ASD, have a family member with ASD, or have some opportunity to interact with the issues posed by individuals with ASD.

ASD is characterized by a triad of impairments: qualitative impairments in communication, qualitative differences in social interaction, and a restricted range of interests. These impairments affect the ability of individuals with ASD to participate in and benefit from many typical educational, care, and recreational settings without specialized intervention. What we know about ASD, however, is that with early, intensive, and specialized intervention many individuals with ASD will succeed in school, work, and in the community. ASD is a spectrum disorder. This means that individuals with this disorder are going to vary with how they are affected and how severely they are affected. There is also a wide variation in how individuals with ASD respond to intervention. Although we know that all individual with ASD benefit from intervention, it is impossible to predict who will benefit the most from what types of intervention. This variation in the severity of the disorder and individuals' response to intervention mandates that decisions about the effectiveness of any intervention for ASD must be based on data.

Individuals with ASD are people first and therefore are entitled to all of the services and privileges that all residents of Washington State enjoy. That means that it is the paramount duty of our state to educate students with ASD and to insure that adults with ASD have access to the same level of services and supports as do other citizens. Although individuals with ASD are entitled to the same services and supports as other citizens, this level of service may not be sufficient to promote positive outcomes. We can say that the existing level of supports (e.g., general education) may be necessary but not sufficient for individuals with ASD.

The members of Washington State Autism Task Force believe that individuals with ASD should be included in every aspect of our communities. As young children, individuals with ASD should be included in child care programs and communities centers. When children hit school age, they should be included to the greatest extent possible in general education and extra curricular activities. As adolescents, individuals with ASD should be included in activities in their communities, in their schools, and in community colleges. As adults, individuals with ASD should be able to find satisfying work, a safe place to live, and a productive way to contribute to the community.

To achieve these goals, the members of Washington State Autism Task Force believe we need to make significant investment and changes in four areas.

These areas are:

- Infrastructure
- Treatment
- Training
- Funding

The task force report includes specific recommendations and background information in all four of these areas. These four areas are a compilation of a number of suggestions and concerns that were raised by task force members and by people who shared information with the task force members. In this summary we will identify the global themes and primary recommendations across these areas and then outline some of the other global themes that were discussed in the task force meetings.

Infrastructure

It is the recommendation of the Washington State Autism Task Force that we develop a minimum of four regional centers to provide services to people with ASD, their families, and professionals. These regional centers would enable our state to meet the needs of individuals with ASD across the state. They would be hubs for assessments, training, consultation and support. Activities would include, but not be limited to:

- Regional workshops, in-service training, and consultation to birth-to-three centers, schools, community agencies, and mental health settings.
- Offer expanded summer intensive training courses for parents and professionals that could accommodate parents and teachers from throughout the state.
- Develop web-based interactive “webinars” that would allow remote access and direct participation in courses offered by Regional Center staff.
- Develop a telemedicine model for autism consultation to health professionals and teachers whereby consultation to professionals can occur remotely via videoconferencing.
- Create and disseminate brochures, PDFs, informational videos, newsletters to provide information to parents and professionals.

These regional centers would not supplant existing services or supports. Rather they would add much needed capacity to an underserved population. These centers would be matched to the regional needs of the states and the unique population of each area of our state.

Treatment

ASD is a lifelong disability. With the improvements in early diagnosis and interventions, we have seen many young children with ASD make remarkable improvements and be successful in school and life with minimal supports and modifications. There are, however, many adolescents and adults with ASD who require ongoing support and services in multiple domains (e.g., vocational, transportation, residential).

It is the recommendation of the Washington Autism Task Force that young children (birth to five) receive a minimum of 25 hours of appropriate services as soon as there is a credible suspicion by the IFSP/IEP team that the child has ASD. These services should include opportunities for the child with ASD to interact successfully with typically developing peer every day. The services must be high quality, data-based, and use evidence based strategies to facilitate positive outcomes for children.

It is the recommendation of the Washington Autism Task Force that school age individuals (5-21) with ASD receive a minimum of 30 hours a week of appropriate services. This level of services and supports should extend to adults in the form of access to secondary education and vocational training.

It is the recommendation of the Washington Autism Task Force that individuals with ASD, their families, and caregivers have access to publicly funded wrap around services including respite care, after school programs, summer programming, and when necessary, residential care.

Training

Meeting the needs of individual with ASD is a complex undertaking. A prerequisite to meeting these needs is having well trained professionals and well informed families and caregivers. It is the recommendation of the Washington Autism Task Force that our state provide on-going training for professionals (across multiple disciplines) and paraprofessionals working with individuals with ASD. Education and support programs should also be provided for family members and other caregivers with ASD. These training programs must be on-going, culturally sensitive, and provided in different languages. These training activities should be provided through the regional autism centers described above.

Funding

Meeting the needs of individual with ASD is a complex and expensive undertaking. The recommendations of the Washington Task Force will require new funding to implement. It is the recommendation of the Washington Task Force that the legislature explore new funding sources including accessing Medicaid funding, blending funding sources across existing programs, and fully funding basic and

special education. The recommendations above, including the regional autism centers and minimal treatment goals for individuals with ASD, will require new funding and must be funded adequately to meet the need of individuals with ASD in Washington State.

These recommendations provide a rudimentary outline for establishing services and supports for individuals with ASD and their families in Washington State. They are not meant to be a comprehensive listing of issues and concerns facing individuals and families, or to represent the entire deliberations of the task force. The global concerns listed below are a collection of issues that were raised during task force meetings.

Global Concerns Facing Services and Supports for Individuals with ASD

Evidence Based Practices

Using research to inform practice in the fields of medicine, education, allied health, and other fields related to behavioral health is becoming standard practice. When providing services to individuals with ASD it is essential to look at the research literature for what has been proven to be effective and to continue to evaluate services at the level of individuals. One of the challenges of working with individuals with ASD is that there is such wide variation in how the disorder presents and how individuals respond to intervention. Therefore, it is essential that we use existing evidence to make initial choices about interventions, and that we collect ongoing data about how the individual responds to the intervention to determine its effectiveness.

Understanding of Autism at Community Level

Almost everyone who presented to the task force – parents of individuals with ASD, individuals with ASD, and professionals across disciplines – were concerned about the lack of knowledge and understanding that existed in the community about ASD. Many parents related stories about people in the community who were intolerant of behaviors demonstrated by children with ASD and how some people assumed these behaviors were due to “bad and over indulgent parenting.” Some adults with ASD described how it was difficult for them to maintain employment because of misunderstandings by colleagues and supervisors of behavior related to the disorder. Professionals who work with students with ASD and vocational counselors who work with adults with ASD described colleagues in schools and workplaces who were resistant to needed accommodations because of lack of understanding of the complexities of needs of individuals with ASD. Clearly, there is a need for education for the citizens of our state about ASD and what individuals with ASD need to be successful. This is starting to take place with a series of Public Service Announcements that are being funded by the CDC and Autism Speaks. More education is needed and this education is the first step towards the full inclusion of people with ASD into our society.

In the recommendations outlined above much attention was given to training. These training activities include service providers across disciplines, family members (extending beyond parents to include grandparents, aunts and uncles, and siblings), individuals who are in decision making positions at schools, state agencies, and funding sources (e.g., Medicaid). This specialized training is essential to insure adequate programming for individuals with ASD. If, however, we want to go beyond adequacy of services and move towards the full inclusion of individuals with ASD training must move outside of professionals and family members to include all members of our community.

Life Long Services and Supports

ASD is a lifelong disability. Despite very good advances in intervention and the success experienced by many individuals with ASD, most people with ASD will need some level of specialized supports and services throughout their lifetime. Task force members were impressed with the need of specialized services across the lifespan of individuals with ASD. These services need to be consistent, comprehensive, high quality, publicly funded, and of necessary intensity to facilitate appropriate outcomes. Although this list is not comprehensive, it is necessary to provide services across the following areas:

- Early Screening, Diagnosis, and Referral to Intervention
- Early Learning and Care
- School Age
- Secondary Education
- Adult Vocational Services
- Long Term Care

Residential Options

Issues around residential services are also a concern for individuals with ASD. These issues fall into three main categories. First, although it is always preferable for children to live with their parents, there are situations when challenging behavior or severe support needs makes it impossible for children with ASD to remain at home. Currently there is an extreme dearth of residential options for children with ASD in our state. Not only are there few options, there are even fewer high quality options that are publicly funded. Residential options for children and young adults with ASD, both short and long term, are necessary.

Second, it is a normal part of the lifecycle, in many western cultures, for young adults to move out of their parents' home to live independently or with friends. Our state needs to provide residential options for young adults with ASD. These options need to include a continuum of options with varying supports that individuals can access.

Finally, individuals with ASD have normal life expectancy. Therefore our state needs to provide options for adults with ASD throughout their lifetime. These options may include independent living, group homes, or more creative individualized options.

Consistency of Services Across the State

Task force members were impressed with reports (and their own experiences) of the difficulty that many individuals with ASD and their families have in accessing high quality services. These difficulties are even more pronounced outside of the greater Seattle area. These difficulties were also more pronounced for individuals and their families who are culturally and linguistically diverse. It is a priority of the task force that all individuals with ASD and their families in Washington State can access high quality, publicly funded services in their own communities with no waiting lists.

Community Supports/Family Support/Inclusion/Respite

ASD is a 24/7 disorder that affects individuals 365 days a year (and 366 days in leap years). Public schools run 180 days a year, 6 hours a day. Many other public services may occur once a week or even less frequently. It is necessary that individuals with ASD and their families have wrap around services that facilitate their success in community and home. These services include but are not limited to funded respite care, parent training, in-home behavior management intervention as needed, recreational programs, summer programs, child care programs, and extended day programming.

Funding

Programs for individuals with ASD and their families are complex and multi-faceted. They are also expensive. It is the duty of Washington State to adequately fund these services. This will require that agencies work together to develop creative strategies for blending and accessing funds. It will require us to look to other states (e.g., Maryland, Pennsylvania) who have addressed this funding challenge and it will require that our state create an infrastructure that will support individuals with ASD and their families.